

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2751001

Exhibits: WITN2751002

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. GRO-B
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2. This witness statement has been prepared without the benefit of access to my medical records.

Section 2. How infected

3. I was infected with Hepatitis C (HCV) from a blood or plasma transfusion some time between 1983 and 1989. During this period I had 4 renal transplants, and numerous other operations at Guys Hospital, London including:

- The insertion of tubes to drain my kidneys
- The removal of two failing transplanted kidneys

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- A kidney biopsy, which resulted in my bowel being punctured in error and becoming infected. This meant that a portion of my bowel had to be removed.
 - Colostomy bag removal
 - Adenoids removal
 - The insertion of grommets
 - Fistulas inserted in both arms
 - A gortex graft to my right leg
 - The insertion of various shunts and drainage tubes.
4. The dates of my kidney transplants were 1st July 1984, 2nd December 1984, 3rd August 1985 and 4th August 1989.
5. I exhibit at WITN2751002 a letter from Guys Hospital dated 3rd January 2019 listing some of my various medical diagnoses.
6. My parents were not provided with any information or advice before any of my operations about the risk of me being exposed to infections from transfusions.
7. I was infected with Hepatitis C as a result of my treatment at Guy's Hospital, London.
8. My parents cannot remember the date they were told I was infected, but my mum can remember being asked if her and my Dad could be tested for Hepatitis C, which they were. After they were tested, we were then referred to Kings College Hospital. My parents recall a female Italian consultant at the paediatric unit at Kings College Hospital telling them that I had Hepatitis C. I believe that this happened in around 1990 when I was about 7 years old. I remember the appointment as it was in a different hospital to the one we normally went to. My mum thinks I was at the appointment when they found out, but I was not in the room.
9. My parents recall being informed that Hepatitis C could cause cirrhosis of the liver and even though there was treatment available for Hepatitis C there was

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not treatment which was suitable for me, because I had previously had four kidney transplants and the treatment would attack my transplanted kidney. My parents recall being told that there was nothing they could do other than monitor me, which they recall being told they would.

10. My parents recall being warned that they needed to be careful around my blood and not to share tooth brushes with me.

11. My parents told me I had Hepatitis C when I was about nine or ten years old. The first I knew of it was when I had a liver biopsy at Kings College Hospital. I suddenly had to start going from the kidney unit to the liver unit. I was confused about why I needed to go to the liver unit.

12. I do not remember being spoken to by a doctor about Hepatitis C until I was a lot older. I believe it was around the time I was transitioning from the children's unit to the adult unit at Guy's Hospital. One of the renal consultants spoke to me about Hepatitis C. He told me not to share tooth brushes or razors. My mum is sure she told me to be careful about sharing toothbrushes and razors etc. before I had this conversation with the consultant.

13. My parents and I absolutely believe that information regarding my Hepatitis C should have been provided to us earlier. We do not believe we were told in a timely manner. We believe that my treating consultants at Guy's hospital would have been aware that I had Hepatitis C some considerable time before my parents were told about my infection.

14. There could have been a huge gap between when I contracted Hepatitis C and when my parents were told of my infection. This could have put my family, the nanny I had at the time and my friends in danger of being infected. We have never asked the rest of my family or my former nanny to be tested.

Section 3. Other Infections

15. I do not believe I have received any other long term infections as a result of my treatment. I believe I have received short term infections as a result of my blood or plasma transfusions, namely urinary tract infections, a bowel infection and infected tubes from stents.

Section 4. Consent

16. My parents believe I was treated and tested without their knowledge, consent and without adequate and full information.

17. We do not know if I was tested for research purposes. The only research I consented to was with student doctors and it did not involve my transfusions or Hepatitis C.

Section 5. Impact of the Infection

18. I have to constantly juggle hospital appointments. Due to my health problems I have to visit six different hospital departments and I have to travel up and down the country, which is tiring for me with my Hepatitis C. I have to attend the liver unit at Guys hospital every three months.

19. The Hepatitis C is just another illness to worry about on top of my other health conditions.

20. I also suffer from physical symptoms which I believe are due to Hepatitis C. I feel tired all the time and have to have a nap every day for a minimum of two hours. Around twice a month I suffer from migraines.

21. As a child I used to get jaundice and sleep excessively for my age in nursery, which we suspect may have been due to my Hepatitis C, but my parents had not been told of my infection at that point.

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22. As a result of my Hepatitis C, I also have cirrhosis of the liver. To the best of my knowledge, I was told I had cirrhosis when I was in my mid 20's.
23. My liver function fluctuates.
24. I require iron and B12 transfusions due to my tiredness.
25. I have a very weak immune system.
26. In terms of treatment, I received Harvoni clearing treatment in 2018 for three months.
27. I could not have clearing treatment before then because the previously available treatment would attack my kidney transplant and my genotype. I believe I was one of the last people to be treated for Hepatitis C because of this.
28. I'm not aware of any other treatments to know if they ought to have been made available for me earlier.
29. The side effects of the Harvoni treatment were relatively severe. I suffered from migraines, bad sickness, diarrhoea, and weight loss. At one point the renal unit said if I lost anymore weight they would have to take me off the Harvoni treatment.
30. The treatment made me anxious, as I was not sure if the side effects were my kidney transplant being rejected or due to the clearing treatment.
31. The Harvoni treatment cleared my Hepatitis C and it is currently undetectable.
32. I have previously contracted E.coli and salmonella, which took months to clear. It was found to be in my native kidneys, which I still had as well as the transplanted one. When my right native kidney was removed the infections cleared.

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33. There is a concern that my left native kidney may still have Hepatitis C in it and that by removing it, it may reactivate the Hepatitis C. However, the kidney is due to be removed at some point in the future.
34. I have had a lot of problems with my teeth and have required extensive dental treatment and I am not sure if this is because of my Hepatitis C. My dental problems are definitely related to my medical conditions.
35. My dental care has to be done at Guy's Hospital because nowhere else will treat me. Other dentists will look inside my mouth but they will not treat me, they just say it is better for me to go back to Guy's hospital.
36. In my early 20's, I was told that I should wait for my jaw to develop properly before I could have more permanent work done on my teeth. Prior to that I had to have steel plates put behind my teeth.
37. My infected status has also had an impact on my medical care. I still have to have surgery at Guy's Hospital because of my kidney problems, and I am always at the bottom of the list, despite sometimes being told that I'm first, which can be very irritating when you have to go nil by mouth pre- surgery. On one occasion, I had to wait sixteen hours before I had an operation. I was starving.
38. I have previously been told by hospital staff that because of my Hepatitis C, they have to clean all of the equipment before I go into theatre and then again afterwards.
39. If I did not have Hepatitis C, I think that my social life would be very different. I have to cancel plans regularly because of how tired I am.
40. Being infected with Hepatitis C has had a big impact on my relationships. At the start of a new relationship I have to tell my partner that I have Hepatitis C, which is difficult.

41. My Hepatitis C has a big impact on my sex life. I do not have a sex drive and mentally I am not sexually active. I never want sex. As a result, my partner and I have an open relationship, because I cannot be physically intimate with him. I find this very hard.
42. Everyone in my family has to look out for me. I have been very protected and wrapped in cotton wool due to my health.
43. I am immature for my age. I think this is due to my lack of time in education and because my family have had to be protective of me for many years.
44. In terms of stigma, to start with, we kept my Hepatitis C private. However, as the years have gone by I am more open about it. There is stigma surrounding Hepatitis C but we fight against it.
45. On one particular occasion I felt affected by stigma. I had to go to the Royal Sussex Hospital for a blood test and they refused to take my blood. I was told that they would have to decontaminate everything as I had Hepatitis C and they were too busy and so I was told that I couldn't have a blood test. My parents made a formal complaint to the hospital about this.
46. For the first six years of my life, I had to go to hospital in London three days a week for kidney dialysis. I spent a lot of time with adults, so at school I was not comfortable around other children and didn't know how to interact with them. As a result, I was bullied a lot at school. To start with, I attended a special primary school. I then attended a mainstream primary school. However, when I was in mainstream school, I used to come home at lunch time because I could not cope with the school environment.
47. When I transferred to a mainstream senior school it resulted in me being bullied even more. At times I had jaundice and yellow teeth and eyes and some of the children would call me 'yellow pages'. I had to try and find older kids to look out for me.

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48. As a child my concentration was very poor as I was always tired, so my school work suffered. I had to have one to one help throughout school. For my exams, I had extra time because of my health conditions.
49. My parents also paid for me to have extra tuition for my hand writing and arithmetic. I found it difficult to use a pen and paper when I was at school and I had to use a laptop. I missed so much school due to my various medical appointments and due to tiredness that my writing skills didn't get a chance to develop properly. Even with the extra tuition, I still cannot read or write very well.
50. I didn't do very well in my GCSE's. Two of my exam papers were classed as ungradable, and in the rest of my subjects I got D's, so my results were below average.
51. After school, I studied and passed a level 3 NVQ in catering and hospitality.
52. I then got a part time job as a hotel porter.
53. I now work for a company called GRO-B
GRO-B I work on average one day a week because of my health. If I do more than sixteen hours a week I'm exhausted. I try to do split shifts or work alternate days to help.
54. I only work at weekends due to having to attend medical appointments in the week and due to my energy levels.
55. Once I have had a B12 or an iron transfusion I can work more hours, but that will only last for a few weeks. I receive iron transfusions regularly, but the B12 transfusions I only receive once every six weeks. I have never been able to work full time because of the fatigue I experience due to my Hepatitis C.
56. As I have never been able to have a full time job, financially I have relied on my parents and my partner. I can only afford to live with my partner due to the

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financial support I receive from my parents. I have been fortunate that my parents are in a position to support me.

57. My parents used to be able to claim to get my train fares reimbursed at the start but they can't anymore.

58. I have to try and get my medical appointments after 11.15am so I can buy the cheapest train tickets. At the moment, a day return travel card to London costs £16.30 if I have an appointment from 11.15 onwards, but this can go up to £45 if I have an earlier appointment. I get frustrated if I have to attend an earlier appointment, but they are delayed and do not see me until after 11.00am, as this is just wasting money I do not have to waste.

59. My health problems have had a huge impact on my parents. They never went on to have another child. The amount of time they have had to spend looking after me meant it wasn't practical for them to have more children

60. My parents have always been supportive and tried to protect me. Even now my mum still has to spend a lot of time caring for me. My parents have to make sure I am eating and taking my medication when I am meant to. They regularly have to put me "back on track", because my chronic fatigue and poor concentration often make it impossible for me to look after myself properly.

61. My Hepatitis C infection has also affected my partner's life. He is not used to being with someone who is in and out of hospital all the time. He is constantly worrying that when I go into hospital I may not come out again and some of this is related to my hospital appointments for Hepatitis C. He has found it very difficult, and so have his parents. He sometimes cannot stay in hospital with me because it gets too much for him.

Section 6. Treatment/care/support

62. As mentioned above, I have faced difficulties obtaining dental care. I have also had to wait a long time for a clearing treatment to become available.

63. I have never been offered counselling or psychological support as a result of my Hepatitis C infection. I think it would have been helpful if it had been made available to me.

Section 7. Financial Assistance

64. I believe I found out financial assistance was available in around July 2004. I was told by the liver consultant at Guy's hospital that there were funds available and he gave me an application form for the Skipton Fund. My family didn't know about any other available funds.

65. I received £20,000 from the Skipton fund by way of the stage 1 payment on 21st September 2004.

66. We kept checking if I was eligible for the stage 2 payment, but I didn't meet the threshold.

67. I now receive monthly payments. I used to receive £250 a month from the Skipton Fund. It increased to £1,500 a month when it changed over to EIBSS.

68. In order to apply for monthly payments from the Skipton fund, I had to get a doctor to write a letter confirming my infection and my award was assessed.

69. When the Skipton fund changed to EIBSS you had to fill in another application form. It was very detailed and you had to get consultant and GP letters again. EIBSS did reimburse us for the consultant's and doctor's letters.

70. I have found the application process for the monthly payments stressful.

71. There was a deadline to submit applications to EIBSS. When I was waiting to see if my application had been successful, people in infected blood groups on social media were commenting on the outcome of their applications and this made it more stressful. Some people were being accepted and some were not. It felt like a lottery. People were also notified at different times, which felt unfair.

72. In terms of preconditions, you had to prove by way of a doctor's letter that you had been infected as a result of receiving blood products, transfusions or other means. Also, I never qualified for the stage 2 Skipton payments as I was not far enough over the liver function test threshold.

73. I was awarded a monthly payment of £1,500 and an annual £500 winter fuel allowance. However, six months later I was then told I had been overpaid and my monthly award was reduced to approximately £1,200 a month. I had to repay the overpayments.

74. Since December 2018 my monthly payments returned to £1,500 a month and I am still awarded the annual £500 winter fuel allowance.

75. I believe everybody should have been treated the same in respect of financial assistance. I would not want to say that the financial support I have received has been unfair, but if my parents didn't support me I couldn't live off the amount of financial assistance I have received from the Skipton fund/EIBSS.

76. My monthly payments increasing in March was helpful, but I could have done with that level of payment from the start, due to my inability to earn enough money to support myself.

Anonymity, disclosure and redaction

77. I wish to remain anonymous.

78. I do not wish to give oral evidence to the Inquiry.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed...

GRO-B

Dated 19 FEB 2019